# **Advance Care Planning**

### References

References in this list are cited in the e-learning course, Advance Care Planning: An Introduction for Public Health and Aging Services Professionals, available on the Web at <a href="http://www.cdc.gov/aging/advancecareplanning">http://www.cdc.gov/aging/advancecareplanning</a>.

Some references contain links to websites of nonfederal organizations. This graphic notice () means you are leaving an HHS website and linking to a site that provides information referenced in this course. Although content is referenced, the Department of Health and Human Services (HHS) cannot attest to the accuracy of a nonfederal site. Linking to a nonfederal site does not constitute an endorsement by HHS or any of its employees of the sponsors or the information and products presented on the site. You will be subject to the destination site's privacy policy when you follow the link.

#### **Module 1-Making the Case**

- 1. Tyler B, Perry M, Lofton T, and Millard F. *The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions, and Attitudes Concerning End-of-Life-Care*, A Report to the Robert Wood Johnson Foundation prepared for American Health Decisions, 1997.
- 2. Tyler B, Perry M, Lofton T, and Millard F. *The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions, and Attitudes Concerning End-of-Life-Care*, A Report to the Robert Wood Johnson Foundation prepared for American Health Decisions, 1997.
- 3. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). *The Journal of the American Medical Association 1995*; 274: 1591—1598.
- 4. Cohn D, Taylor P. Baby Boomers Approach Age 65—Glumly. Survey Findings about America's Largest Generation.

  <a href="http://pewresearch.org/pubs/1834/baby-boomers-old-age-downbeat-pessimism">http://pewresearch.org/pubs/1834/baby-boomers-old-age-downbeat-pessimism</a>
- 5. Goulding MR, Rogers ME, Smith SM. 2003. Public health and aging: trends in aging—United States and worldwide. *Morbidity and Mortality Weekly Report* 2003: 52(06):101—106. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm
- 6. National Alliance for Caregiving, AARP; Caregiving in the United States 2009. http://www.caregiving.org/data/Caregiving in the US 2009 full report.pdf
- 7. U.S. Department of Health and Human Services. *Multiple Chronic Conditions—A Strategic Framework: Optimum Health and Quality of Life for Individuals with Multiple Chronic Conditions.* Washington, DC: U.S. Department of Health and Human Services, 2010.
- 8. Smolka G, Purvis L, Figueiredo C. Health care reform: What's at stake for 50—to 64-year-olds? AARP Public Policy Institute Insight on the Issues. AARP website. http://assets.aarp.org/rgcenter/health/i24 hcr.pdf
- 9. Anderson G. Chronic Conditions: Making the Case for Ongoing Care, September 2004 Update. Baltimore, MD: Partnership for Solutions; 2004. http://www.partnershipforsolutions.org/DMS/files/chronicbook2004.pdf
- 10. Anderson G. Chronic Conditions: Making the Case for Ongoing Care. Baltimore, MD:P Johns Hopkins University; 2004.

  <a href="http://www.rwjf.org/files/research/50968chronic.care.chartbook.pdf">http://www.rwjf.org/files/research/50968chronic.care.chartbook.pdf</a>
  Last accessed December 2, 2010.
- 11. Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 census." *Archives of Neurology* 2003;60:1119—1122.



- 12. Emanual EJ. Cost savings at the end of life: What do the data show? JAMA 1996;275:1907—1914.
- 13. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Laciejewski ML, et al. Health care costs in the last week of life. *Arch Intern Med* 2009;169(5):480—489. http://www.ncbi.nlm.nih.gov/pubmed/19273778
- 14. Rao JK, Anderson LA, Smith SM. End of life is a public health issue. *American Journal of Preventive Medicine* 2002;23(3):215—220.
- 15. Improving End-of-Life Care. *NIH Consens State Sci Statements*. 2004 Dec 6−8; 21(3) 1−28. http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024PDF.pdf 🗗

#### **Module 2–The Essential Elements**

- 16. Pew Research Center for the People & the Press. Strong public support for right to die: More Americans discussing—and planning—end-of-life treatment. Telephone survey of 1,500 older adults conducted Nov. 9-27, 2005 under the direction of Princeton Survey Research Associates International. Released January 5, 2006. http://people-press.org/report/266/storng-public-support-for-right-to-die
- 17. Jorgenson A. Cultural perspectives on death. *AAHPM Bulletin* 2005;6(2):7. http://www.aahpm.org/pdf/05summer.pdf

## Module 3-Making a Difference

- 18. Thomson Reuters. National Survey of Healthcare Consumer: End-of-Life Care. http://www.factsforhealthcare.com/pressroom/NPR report EndofLifeCare0710.pdf
- 19. Pew Research Center for the People & the Press. Strong Public Support for Right to Die: More Americans Discussing— and Planning—End-of-Life Treatment. Telephone survey of 1,500 older adults conducted Nov. 9-27, 2005 under the direction of Princeton Survey Research Associates International. Released January 5, 2006. http://people-press.org/report/266/storng-public-support-for-right-to-die
- 20. Tobler L. Planning for end-of-life care. *LegisBrief* 2010;18(34).
- 21. Miniño, A; Xu, J; Kochanek, KD. "Deaths: preliminary data for 2008." *National Vital Statistics Reports*. 2010;59(2). http://www.cdc.gov/nchs/data/nvsr/nvsr59/nvsr59\_02.pdf
- 22. Johnson SH. Introduction: Relieving unnecessary, treatable pain for the sake of human dignity. *Journal of Law, Medicine & Ethics* 2001;28(s4):11—12.
- 23. Last Acts. Pain Management: Advances in State Pain Policy and Medical Practice. State Initiatives in End-of-Life Care. Princeton NJ: Robert Wood Foundation: 1999. http://www.rwjf.org/files/publications/other/State Initiatives EOL4.pdf
- 24. Ferrell BR. The impact of pain on quality of life: A decade of research. *Nursing Clinics of North America* 1995:30(4):609—624.
- 25. Gilson AM, Joranson DE, Maurer MA. Improving state pain policies: recent progress and continuing opportunities. *CA Cancer J Clin* 2007;57:341—353.
- 26. Stewart WF, Ricci JA, Chee E, et al. Lost productive time and cost due to common pain conditions in the U.S. workforce. *JAMA* 2003;290:2443—2454.

- 27. Pain & Policy Studies Group, *Achieving Balance in Federal and State pain Policy: A Guide to Evaluation (Third Edition)*. September 2006. University of Wisconsin School of Medicine and Public Health website.

  <a href="https://scholarworks.iupui.edu/bitstream/handle/1805/826/Achieving%20balance%20in%20federal%20and%20state%20pain%20policy%20-%20part%201.pdf?sequence=1">https://scholarworks.iupui.edu/bitstream/handle/1805/826/Achieving%20balance%20in%20federal%20and%20state%20pain%20policy%20-%20part%201.pdf?sequence=1</a>
- 28. Memorial Sloan- Kettering Cancer Center. Pallative Care and Pain Management. Memorial Sloan-Kettering website.

  <a href="http://www.mskcc.org/mskcc/html/474.cfm">http://www.mskcc.org/mskcc/html/474.cfm</a>. <a href="http://www.mskcc.org/mskcc/html/474.cfm">http://www.mskcc.org/mskcc/html/474.cfm</a>.
- 29. World Health Organization. Definition of Palliative Care. World Health Organization website. <a href="http://www.who.int/cancer/palliative/definition/en/">http://www.who.int/cancer/palliative/definition/en/</a>.
- 31. National Hospice and Palliative Care Organization (NHPCO). NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, October 2010. <a href="http://www.nhpco.org/files/public/Statistics">http://www.nhpco.org/files/public/Statistics</a> Research/Hospice Facts Figures Oct-2010.pdf.
- 32. National Hospice and Palliative Care Organization (NHPCO). NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, October 2010. <a href="http://www.nhpco.org/files/public/Statistics">http://www.nhpco.org/files/public/Statistics</a> Research/Hospice Facts Figures Oct-2010.pdf.